

VIII. DESIGNING THE NFCSP IN THE CONTEXT OF DIVERSE CAREGIVER POPULATIONS

This chapter aims to guide administrators and program planners of State Units on Aging (SUAs), Area Agencies on Aging (AAAs), Service Providers (SPs) and Indian Tribal Organizations (ITOs) in designing services to meet the needs of individual caregiver subpopulations. The following general strategies for reaching and serving specific caregiver subpopulations are reflected throughout this chapter:

- Establish implementation goals based on needs and resources in particular regions and local communities.
- Involve caregiver stakeholders in the implementation process at the state, regional, local and tribal levels.
- Educate and train staff on the most effective approaches for reaching and serving specific subpopulations.
- Employ culturally competent communication tactics that ensure outreach, assistance, education, and referral efforts are communicated through methods proven effective in reaching particular subpopulations (e.g., targeting ethnic groups in locations where they are likely to live).
- Maximize resources by forming partnerships with existing advocacy organizations and health, social service, and other community entities already specializing in advocacy efforts or services relevant to a specific subpopulation.
- Build flexibility in the program so it can respond to individual characteristics, preferences, and needs.

Caregivers represent a heterogeneous group of subpopulations, each with different demographic, circumstantial, and environmental factors influencing the caregiver experience. This chapter presents the type of NFCSP services needed by particular caregiver subpopulations within the following three domains.

1. Demographic Factors
 - Ethnicity, race, and culture
 - Sexual orientation
2. Special Caregiver Circumstances
 - Grandparents and other relatives raising children
 - Older caregivers of children and young adults with developmental disabilities

3. Environmental and Other Conditions

- Working caregivers
- Rural caregivers
- Long-distance caregivers

Presenting service needs by subpopulation in this chapter highlights the relevance of designing programs in the context of specific demographic factors and other caregiver circumstances. The subpopulations represented, however, overlap with one another (e.g., rural caregivers include minority groups). Also, significant overlap exists in the types of challenges caregivers face across subpopulations (e.g., rural and long-distance caregivers both face geographic obstacles in coordinating services for care recipients).

In discussing each subpopulation, the chapter incorporates the available evidence in the literature and provides program examples and strategies used by states experienced in designing program models for diverse caregiver populations. The lessons learned in states can inform the network's efforts to address both the subtle and palpable needs of caregivers.

DEMOGRAPHIC FACTORS

Designing an effective National Family Caregiver Support Program (NFCSP) calls for consideration of demographic factors influencing the needs of caregivers, including ethnicity, race, culture, socioeconomic status, and sexual orientation. These factors affect the type of support that a caregiver needs, how or whether he or she seeks and receives services, and the duration of services required. Some caregivers need information, some seek emotional support, and others require assistance with direct care tasks. Caregiver interventions might be intensive initially, until the family's situation stabilizes, and then intermittent, as new challenges arise.¹

Ethnicity, Race, and Culture

Ethnic and racial minorities age 65 and over are increasing faster than other segments of the population, and by 2030, minority groups are projected to comprise 25 percent of the older population.² This trend holds significant implications for the aging network's role in responding to the needs of caregivers supporting the aging minority population.

The U.S. Census Bureau broadly categorizes ethnic and racial populations into four groups (African American, Asian American and Pacific Islander, Hispanic American, and

¹ Montgomery, R.J.V. and Kosloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

² Angel, J.L. and Hogan, D.P. (1994). *The Demography of Minority Aging Populations. Minority Elders: Five Goals Toward Building a Public Policy Base*. Washington, DC: The Gerontological Society of America.

American Indian/Alaska Native); however, many other racial or ethnic minorities and considerable diversity exist within each group. National data indicate that 28 percent of African Americans, 42 percent of Asian/Pacific Islander Americans, and 34 percent of Hispanic Americans provide care to their aging parents, in-laws, or other relatives.³

Recognition of cultural differences in racial and ethnic populations from the larger caregiver population is an important component of implementing the NFCSP. “The term ‘culture’ connotes a common heritage and set of beliefs, norms and values. Within any given group, an individual’s cultural identity involves multiple layers, including language, country of origin, gender, age, class, religious/spiritual beliefs, acculturation,⁴ sexual orientation, and physical disabilities.”⁵

The literature documents numerous barriers to treatment by racial and ethnic minorities, including cultural, organizational, poverty, and income limitations. Similar to other health care service recipients, caregivers’ cultural identities can influence practices that affect their willingness to seek, and ability to respond to, health and social services. Significant culture-related barriers to care exist for racial and ethnic minorities in part because the health and social service systems historically have ignored the unique needs of these groups.

Until recently, research on caregivers has focused almost exclusively on non-minority caregivers.^{6 7} Despite limited research in this area, lessons learned from national research studies such as the Alzheimer’s Disease Demonstration Grants to States (ADDGS)⁸ program and the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) program, identify several mechanisms for state and local agencies to respond to the needs of minority groups.⁹

³ Gallagher-Thompson, D., Haley, W., Guy, D., Rubert, M., Tennstedt, S., and Ory, M. (2002). Tailoring Psychosocial Interventions for Ethnically Diverse Dementia Caregivers. Unpublished manuscript.

⁴ Acculturation refers to the “social distance” separating members of an ethnic or racial group from the wider society in areas of beliefs and values and primary group relations (work, social clubs, family, friends). Thus, greater acculturation reflects greater adoption of mainstream beliefs and practices and entry into primary group relations. Taken from Gordon, M.F. (1964). *Assimilation in American Life*. New York, NY: Oxford University Press.

⁵ Lu, F.G., Lim, R.F., and Mezzich, J.E. (1995). Issues in the Assessment and Diagnosis of Culturally Diverse Individuals. *Review of Psychiatry*. Washington, DC: American Psychiatric Press.

⁶ Connell, C.M. and Gibson, G.D. (1997). Racial, Ethnic, and Cultural Differences in Dementia Caregiving: Review and Analysis. *The Gerontologist*. Vol. 37.

⁷ Aranda, M.P. and Knight, B.G. (1997). The Influence of Ethnicity and Culture on the Caregiver Stress and Coping Process: A Sociocultural Review and Analysis. *The Gerontologist*. Vol. 37.

⁸ The ADDGS program is authorized in Section 398 of the Public Health Service Act (42 U.S.C. 398 et seq.), as amended by Public Law 101-157 and by 105-379, the Health Professions Education Partnership Act of 1998.

⁹ REACH is a five-year, multi-site study funded by the National Institutes of Health (NIH), the National Institute on Aging (NIA), and the National Institute on Nursing Research (NINR). The project measures effectiveness of various interventions for family caregivers and maintains six intervention sites throughout the United States.

Strategies and Program Examples

The NFCSP provides the network with an opportunity to build on prior efforts to design caregiver and care recipient services that are culturally competent. Cultural competence is defined as “a set of cultural behaviors and attitudes integrated into the practice methods of a system, agency, or its professionals.”¹⁰ Cultural competence has proven effective in increasing utilization and improving services for minority populations across a range of health care sectors.¹¹

Employing strategies to achieve cultural competence ensures that The aging network can work effectively in cross-cultural situations. The following section presents some of the key approaches for moving toward a culturally competent system:

- Demonstrating a commitment to responding to cultural diversity.
- Providing population-based service delivery to maximize cultural strengths and minimize barriers to care.
- Partnering with community organizations already dedicated to addressing the needs of specific minority groups.
- Tailoring communication style to the target population.

Demonstrate Commitment to Responding to Cultural Diversity. The aging network can demonstrate its commitment to placing a high priority on recognizing and responding to culturally diverse populations through a range of approaches, including:

- Creating mission statements that articulate principles, rationale, and values for culturally and linguistically competent service delivery;
- Developing mechanisms to assure diverse caregiver participation in the state- and local-level planning, delivery, and evaluation of services;
- Employing policies and practice standards around staff recruitment, hiring, and retention that will achieve a goal of a diverse and culturally competent workforce; and
- Dedicating resources to support training and staff development, as well as outreach, translation, and interpretation services.

An important initial step in identifying and conducting outreach to minority populations involves using data, such as the Census, to identify counties and neighborhoods with high concentrations of minority groups. Other aggregate data might be obtained from community planning agencies, social service departments, and services for new

¹⁰ Lavizzo-Mourey, R. and Mackenzie, E. (1995). Cultural Competence – An Essential Hybrid for Delivering High Quality Care in the 1990’s and Beyond. *Transactions of the American Clinical and Climatological Assoc.* Vol. 107.

¹¹ Cross, T., Bazron, B., Dennis, K., and Isaacs, M. (1989). Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. Washington, DC: Georgetown University Child Development Center.

immigrants. **Chapter III** addresses detailed methods and sources for identifying prevalence estimates of the caregiver population.

Employing bilingual individuals who reflect the ethnic backgrounds of the local caregiver community is also a key strategy for outreach and service provision to caregivers. Some states, such as California, require all caregiver resource centers to employ bilingual staff and provide basic information and educational materials in languages other than English.¹² In addition to recruiting and hiring bilingual staff, training and professional development efforts should ensure that all staff members, regardless of background, understand cultural differences and their impact on attitudes and behaviors. Staff members must be sensitive, understanding, and respectful in dealing with people whose culture differs from their own. Training should also focus on making sure staff members remain flexible and skillful in responding and adapting to different cultural contexts and circumstances.

Aging network agencies can create an advisory committee represented by individuals serving in leadership roles in ethnic communities to offer guidance on how to serve different populations effectively. To enhance minority outreach efforts, network agencies can seek bilingual and minority volunteers from established volunteer organizations, as well, such as AmeriCorps and Retired Seniors Volunteer Program (RSVP).

Decorating network offices with culturally and linguistically friendly pictures, posters, and artwork makes facilities more welcoming and attractive to minority caregivers, thereby enhancing program participation.

Provide Population-Based Service Delivery to Maximize Cultural Strengths and Minimize Cultural Barriers to Care. Knowing and understanding the characteristics of the population being served and delivering population-based services are important methods for developing effective caregiver support programs. An essential step in delivering population-based services is creating or using model burden assessments tailored to evaluate the needs of specific minority groups. **Chapter IV** addresses in detail strategies for developing burden assessments.

This section presents frequently identified strategies in the literature for addressing some of the cultural differences among specific minority groups. African American caregivers, in general, consider aging as a transitional phase of life, and therefore, view family caregiving as a normal expectation, rather than a disruption of the life course.¹³ These

¹² Administration on Aging (2001). *Achieving Cultural Competence, A Guidebook for Providers of Services to Older Americans and their Families*. Washington, DC: AoA.

¹³ Haley, W.E., Roth, D.L., Coletton, M.I., Ford, G.R., West, C.A.C., Collins, R.P., and Isobe, T.L. (1996). Appraisal, Coping, and Social Support as Mediators of Well-Being in Black and White Family Caregivers of Patients with Alzheimer's Disease. *Journal of Consulting and Clinical Psychology*. Vol. 64.

positive perceptions about aging and caregiving contribute to lower levels of stress, such as fewer symptoms of depression and greater satisfaction with the caregiving role.^{14 15 16 17}

African Americans' acceptance of the role of caregiver coupled with support from both family and community members, however, might explain why individuals often wait to obtain caregiver services in the late stages of the caregiving process. Compared with non-minority caregivers, African American caregivers are more likely to provide higher-intensity level of care yet also report having lack of access to caregiver support services. Despite these trends, African American caregivers report limited use of formal support systems.¹⁸

Also important for the aging network is focusing on initiatives that capitalize on the cultural strengths of African Americans and other minority groups. For example, ties to family and community are especially strong in many African American, Hispanic, and Asian communities. As such, program administrators must shift interventions from working with caregivers individually to involving the whole family. When faced with personal difficulties, African Americans have often been known to seek guidance from religious institutions.¹⁹ Services for African Americans that involve family members and churches often prove more effective than other initiatives.²⁰ **Exhibit VIII.1** highlights program examples that target African Americans, as well as other minorities, in community settings familiar to them.

¹⁴ Hinrichsen, G.A. and Ramirez, M. (1992). Black and White Dementia Caregivers: A Comparison of Their Adaptation, Adjustment and Services Utilization. *The Gerontologist*. Vol. 32.

¹⁵ Haley, W.E., West, C.A.C., Wadley, V.G., Ford, G.R., White, F.A., Barrett, J.J., Harrell L.E. and Roth, D.L. (1995). Psychological, Social and Health Impact of Caregiving: A Comparison of Black and White Dementia Family Caregivers and Noncaregivers. *Psychology and Aging*. Vol.10.

¹⁶ Lawton, M.P., Rajagopal, D., Brody, E., and Kleban, M. (1992). The Dynamics of Caregiving for a Demented Elder Among Black and White Families. *Journal of Gerontology: Social Sciences*. Vol. 47.

¹⁷ Mui, A. (1992). Caregiver Strain among Black and White Daughter Caregivers: A Role Theory Perspective. *The Gerontologist*. Vol. 32.

¹⁸ Navaie-Walser, M., Feldman, P., Gould, D., Levine, C., Kuerbis, A., and Donelan, K. (2001). The Experiences and Challenges of Informal Caregivers: Common Themes and Differences Among Whites, Blacks, and Hispanics. *The Gerontologist*. Vol. 41

¹⁹ Broman, C.L. (1996). Coping with Personal Problems. In H.W. Neighbors and J.S. Jackson (Eds.), *Mental Health in Black America*. Thousand Oaks, CA: Sage.

²⁰ Lockery, S.A. (1991). Caregiving Among Racial and Ethnic Minority Elders. *Generations*. Vol. 15.

Exhibit VIII.1 Skills Training for African Americans

<p>Title: Alabama REACH Project</p> <p>Affiliation: University of Alabama in Birmingham, Alabama</p> <p>Status: Operational</p> <p>Target Population: African American and non-minority caregivers of individuals with dementia</p> <p>Approach: The Alabama REACH Project employs several strategies to eliminate observed cultural and socioeconomic barriers to care for African American caregivers. This program involves African American and non-minority staff presenting three-hour skills training workshops in centers known to the African American community (e.g., churches). The key objectives of the workshop are to provide caregivers with accurate information about dementia and to teach behavior management skills to address care recipients' problematic behavior. Another objective involves encouraging caregivers to increase positive health behaviors (e.g., exercise) for themselves. Selecting sites familiar to the community has proven fundamental to reducing workshop absenteeism. Staff members are trained to adapt their teaching strategies to the educational level and learning styles of participants. In follow-up to the workshop, one-on-one in-home training takes place over a three-month period to provide caregivers with ongoing coping skills for potentially stressful circumstances.</p> <p>Contact Information: Louis D. Burgio, Ph.D., Principal Investigator, Director, Applied Gerontology Program, The University of Alabama at Tuscaloosa, at lburgio@sw.ua.edu or (205) 348-7518.</p>

Asian Americans commonly assume more responsibilities for both children and living parents in comparison to other minority groups because many have postponed having children, according to findings from a national survey of African American, Hispanic American, and Asian American caregivers aged 45 to 55. Yet, this group often reports experiencing feelings of guilt for failing to do more. Asian Americans also are apt to express that caring for family members creates stress. In some respects, older Asian Americans in the U.S. have fewer family caregivers available in comparison to other minority groups. They generally have fewer and younger children, or no children at all, to help care for them.²¹

Under use of services among Asian Americans represents a key challenge for providers. Asian Americans refrain from requesting services for a number of reasons, including cultural stigma associated with seeking assistance, limited English proficiency among some Asian immigrants, different cultural explanations for the problems, and the inability to find culturally competent services.²² **Exhibit VIII.2** presents an example of a program in Ohio that has proven effective in reaching Asian Americans.

²¹ AARP (2001). *In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues*. A National Survey Conducted for AARP.

²² Sue, S., Zane, N., and Young, K. (1994). Research on Psychotherapy with Culturally Diverse Populations. In A.E. Bergin and S.L. Garfield (Eds.), *Handbook of Psychotherapy and Behavior Change*. New York, NY: Wiley.

Exhibit VIII.2

Outreach to Asian Americans and African Americans

Title: Central Ohio Area Agency on Aging (COAAA) Outreach Project

Affiliation: Central Ohio AAA

Status: Operational

Target Population: Asian American and African American caregivers

Approach: COAAA is collaborating with several community groups in Columbus, Ohio, to organize effective outreach to Asian American and African American caregivers. Community groups include the Black Church Network and the Asian American Community Services. The agency is conducting workshops to educate caregivers about aging-related disorders, the impact on the entire family, and challenging situations and behaviors. Staff and interpreters go to individuals' homes and communities to inform caregivers about the educational workshops. COAAA uses a range of incentives, such as gift certificates, to encourage minority populations to attend the seminars.

Contract Information: Lisa Durham, Community Education and Outreach Director, COAAA, at durham@coaa.org or (614) 645-7250.

For many Hispanic American caregivers, the combination of high expectations and effort create a heavier caregiver load. Much of this care entails such substantial tasks as supporting older parents financially, giving them personal care, and helping them obtain medical attention.²³

Recognizing that variation exists among caregiver perceptions and preferences within different Hispanic communities (e.g., Mexican, Puerto Rican, Cuban, Central and South American, or Spanish origin) as well as other minorities is important. However, several studies indicate that, in general, Hispanic caregivers experience higher levels of depression, burden, and stress compared with their non-minority or African American counterparts.^{24 25 26 27} Hispanic caregivers also report more dissatisfaction with family support, in part because they tend to internalize stress. Despite Hispanic caregivers' need for assistance, they do not necessarily seek services. Cultural values that place importance on enduring and not complaining publicly about stress contribute to the difficulties associated with the Hispanic population's reluctance to receive services.²⁸

²³ AARP (2001). *In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues*. A National Survey Conducted for AARP.

²⁴ Cox, C. and Monk, A. (1993). Black and Hispanic Caregivers of Dementia Victims: Their Needs and Implications for Services. In C.M. Barresi and D.E. Stull (Eds.), *Ethnic Elderly and Long Term Care*. New York, NY: Springer.

²⁵ Kemp, B. and Adams, B. (1996). *The Role of Caregiver Appraisal, Coping Method and Social Support in the Stress of Dementia Caregivers of Four Different Ethnic Groups: Final Report*. Downey, CA: Alzheimer's Disease Diagnostic and Treatment Center, Rancho Los Amigos Hospital.

²⁶ Mintzer, J.E., Rubert, M.P., and Lowenstein, D. (1992). Daughters' Caregiving for Hispanic and Non-Hispanic Alzheimer's Patients: Does Ethnicity Make a Difference? *Community Mental Health Journal*.

²⁷ Polich, T. and Gallagher-Thompson, D. (1997). Preliminary Study Investigating Psychological Distress among Female Hispanic Caregivers. *Journal of Clinical Geropsychology*. Vol. 3.

²⁸ Valle, R. (1998). *Caregiving across Cultures: Working with Dementing Illness and Ethnically Diverse Populations*. Washington, DC: Taylor & Francis.

Exhibit VIII.3 highlights a program in California that attempts to reduce stress for Mexican American caregivers.

Exhibit VIII.3 **Stress Management for Mexican Americans**

<p>Title: California REACH Project</p> <p>Affiliation: VA Palo Alto Health Care System and Stanford University School of Medicine</p> <p>Status: Operational</p> <p>Target Population: Mexican American caregivers</p> <p>Approach: This program seeks to provide Mexican American caregivers with the resources to address depression and other forms of psychological distress associated with caregiving through a small group (no more than 6 to 10 participants per group) workshop format. During the workshops, well-trained bilingual staff members help caregivers identify negative thoughts and provide them with specific skills to challenge those thoughts. Staff members encourage caregivers to find more adaptive ways to view the situation. To ensure maximum participation, the workshops are always held in community locations near where a majority of the caregivers live. Before implementation, consultation was sought from numerous community leaders primarily representing local Mexican American groups as well as from Hispanic caregiver focus group meetings. Based on clinical observations of staff, the interventions described above appear effective in decreasing the prevalence of caregiver depression and enhancing sense of self-efficacy for continuing in their role.</p> <p>Cost/Funding: Services are free of charge to caregivers, and financial assistance is available as needed for transportation and elder care costs incurred while participating in REACH activities.</p> <p>Contact Information: Dolores Gallagher-Thompson, Veteran Affairs Medical Center, at dolorest@stanford.edu or (650) 493-5000.</p>

Knowledge of issues affecting American Indian caregivers is far less developed than similar research on other minority groups. However, the limited literature underscores some important considerations for ITOs in implementing caregiver support programs. Respect for elders is regarded as a strong central value by American Indians. Unlike their non-minority counterparts, American Indians express less guilt and anger toward their dependent elders. Cultural values tend to encourage acceptance of present-day circumstances, including caregiving. Additionally, American Indians are generally described as “group oriented with individual goals.” Therefore, emphasizing benefits to the community first is important, followed by addressing personal benefits.²⁹

Compared to other communities, many American Indian communities lack core community-based services, such as adult day services and home health, hospice, support

²⁹ John, R., Hennessy, C., Dyeson, T., and Garrett, M. (2001). Toward Conceptualization and Measurement of Caregiver Burden among Pueblo Indian Family Caregivers. *The Gerontologist*. 41(2): 210-219.

group, and other community services.³⁰ A dearth of core services requires that ITOs conduct an assessment of available services and providers and identify opportunities for tribes to pool regional resources for meeting the needs of caregivers. ITOs should consider developing relationships with the providers and assist in making the services culturally appropriate.

In addition to recognizing perceptions and general patterns of care among minority groups, understanding particular groups within minorities is imperative. With more than 550 federally recognized tribes and an additional 365 state-recognized tribes and bands, many differences exist in coping mechanisms for caregivers from tribe to tribe. For example, one study on Pueblo Indian family caregivers found that this population experiences guilt more intensely than other types of caregiver burden. With this knowledge, service providers can initially determine whether the level of guilt is warranted. If the elder is being cared for inadequately, then additional caregiving support services can be procured for the family. If the elder is adequately cared for, but the guilt feelings of the caregiver are based on faulty perceptions, then services of the caregiver should be tailored to provide education and affirmation to the caregiver.³¹ ITOs can conduct focus groups to gather information on caregiver perceptions within various tribes that can inform the service approach under the NFCSP. *Exhibit VIII.4* presents a range of approaches tribes use to implement the NFCSP.

Exhibit VIII.4 **Caregiver Programs for Native Americans**

Title: Care Coordination Program

Affiliation: Sitka Tribe of Alaska

Status: Developmental

Target Population: Caregivers in Sitka tribes

Approach: The main components of this caregiver support program are care coordination and paraprofessional rural care advocacy services. The care coordination system consists of professional care coordinators in Juneau, the hub community. The care coordinators travel to Sitka to meet with individual caregivers, assess their needs, create a plan of care, and arrange for services and benefits. Care coordinators work closely with the Sitka rural care advocate who provides ongoing support to the caregiver. The rural care advocate also provides ongoing outreach in the community to locate caregivers. Counseling services are available to help families cope with the emotional demands of caregiving.

Contact Information: Lawrence Widmark, Tribal Chairman, Sitka Tribes of Alaska, at widmarkw@mail.ssd.kiz.ak.us or (907) 747-3207

³⁰ U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), LTG Associates, Inc. (2001). Geriatric Training Initiative, Cultural Diversity: American Indians.

³¹ John, R., Hennessy, C., Dyeson, T., and Garrett, M. (2001). Toward Conceptualization and Measurement of Caregiver Burden among Pueblo Indian Family Caregivers. *The Gerontologist*. 41(2):210-219.

Exhibit VIII.4

Caregiver Programs for Native Americans, continued

Title: Warm Spring Caregiver Support Program

Affiliation: Confederated Tribes of Warm Springs (Oregon)

Status: Developmental

Target Population: Caregivers in confederated tribes

Approach: This caregiver support program assists individuals caring for frail elderly or individuals with disabilities in their homes. By receiving support, the caregiver becomes less prone to “burn-out.” A coordinated effort is made with the Indian Health Service and state and local social services agencies to identify individuals with the greatest need. Information on the program is available through the Title VI site, one-on-one contract with senior program and social services staff, and the local radio station and newspaper. The program staff also assists in providing advocacy, transportation, coordination of care, and direct services.

Contact Information: Olney Patt, Jr., Chairman of the Tribal Council, or Gayle Rodgers, Confederated Tribes of Warm Springs, at (541) 553-3491.

Title: Family Caregiver Support Program

Affiliation: Red Cliff Band of Lake Superior Chippewas (Bayfield, Wisconsin)

Status: Developmental

Target Population: Native American caregivers

Approach: Among the activities planned are the development of brochures, flyers, and other materials publicizing the availability of caregiver respite services, caregiver support group meetings, and resources available from other agencies. In addition to providing public information, the Red Cliff Band will provide direct assistance to caregivers through the Elder Program administration. The Elder Program administration will act as caseworker and provide referral and assistance services to the caregivers. Respite services will be established within the community to allow for temporary respite for the caregiver.

Contact Information: Kim Gordon, Administrator of Social Services, Red Cliff Band of Lake Superior Chippewas, at (715) 779-3706.

Exhibit VIII.5 summarizes frequently identified strategies described above for addressing some of the cultural differences among minority groups.

Exhibit VIII.5
Strategies for Addressing Cultural Differences

Minority Population	Cultural Differences among Minority Groups	Strategies for Responding to Cultural Differences
African American	<ul style="list-style-type: none"> ▪ Employ coping mechanisms such as reliance on religious faith or prayer. ▪ Share caregiving responsibilities among a number of households and family members, including parents, adult children, siblings, and other relatives. ▪ Use cognitive strategies often, such as re-framing the situation and positive self-statements, consequently experiencing lower levels of stress. 	<ul style="list-style-type: none"> ▪ Use approaches designed to meet the needs of the family, rather than solely the individual. ▪ Include spiritual themes and reference prayer as a form of coping, and hold educational workshops in a church setting.
Asian/Pacific Islander	<ul style="list-style-type: none"> ▪ Experience feelings of guilt often and believe they should be doing more, despite significant level of engagement in caregiving. ▪ Experience high levels of stress associated with caregiving due partly to the high value placed on emotional control. ▪ Possess limited English proficiency (many Asian immigrants). 	<ul style="list-style-type: none"> ▪ Conduct focus groups to determine if guilt is an issue in the local community, and if so, understand reasons for guilt and design appropriate services. ▪ Design programs that focus on strategies for reducing stress levels for caregivers. ▪ Translate all program materials to reflect the meaning of the content, rather than literal translation, and ensure appropriateness of materials by seeking input from the Asian/ Pacific Islander community.
Hispanic American	<ul style="list-style-type: none"> ▪ Place high value on interpersonal and social interactions in which individuals deal with one another in a compassionate manner. ▪ Experience high levels of depression and dissatisfaction with family support network in relation to the caregiving experience. ▪ Feel bound by cultural values to endure stress and not complain about it publicly. 	<ul style="list-style-type: none"> ▪ Incorporate a socialization component to engage caregivers in conversation because an interactive and personal approach is crucial for working with this population. ▪ Design programs that focus on strategies for reducing stress levels for caregivers, such as helping caregivers identify negative thoughts and providing them with skills to find more adaptive ways to view the situation. ▪ Focus on intensive outreach efforts, such as using community-based media outlets (e.g., minority newspapers and magazines, minority college campus newsletters, local minority radio and cable television programs).

Exhibit VIII.5
Strategies for Addressing Cultural Differences, continued

Minority Population	Cultural Differences among Minority Groups	Strategies for Responding to Cultural Differences
American Indian/Alaska Native	<ul style="list-style-type: none"> ▪ Place less emphasis on having control over the caregiving situation, and focus more on the positives of managing the needs of a dependent elder. ▪ Place greater priority on the effects of caregiving on the group (i.e., family and tribe), rather than on a caregiver's individual needs. ▪ Value verbal non-assertiveness, and believe verbalizing a problem makes the problem become reality. ▪ Perceive time as a sense of being rather than doing (e.g., find rushing a social or professional encounter disrespectful). 	<ul style="list-style-type: none"> ▪ Define intervention strategies in relationship to the family and community, rather than to the individual, such as emphasizing the impact of caregiving on the entire family or tribe. ▪ Seek tribal members to assist in the development of communication strategies that reflect the values of the culture. Focus areas should include orientation to the present, orientation to a past that honors tradition (e.g., storytelling), oral transmission of knowledge, and discrete communication respecting the individual. ▪ Educate providers on how to alter communication style to respond to different perception of time and allot an adequate amount of time to communicate effectively with individuals during encounters.

Although cultural differences are important considerations, recognizing the heterogeneity within ethnic and racial groups is essential. The aging network should continue to place a high priority on considering individual-level differences (e.g., age, education, length of time spent in the United States, literacy, income, gender, and geographic location) and preferences.

Partner with Community Organizations Dedicated to Addressing the Needs of Minority Groups. The literature clearly establishes the need for formal support services but also indicates that minority caregivers often fail to receive services early in the caregiving process. Lessons learned from the REACH and the ADDGS projects reveal that to effectively reach minority caregivers, establishing partnerships and relationships with key minority leaders and institutions in the community is critical during program implementation. Although initial development of relationships with ethnic minority clients requires a significant amount of staff resources, acceptance of new services rests on gaining trust and support from respected members of the community. Potential groups for collaboration might include:

- Neighborhood government advisory groups,
- Community colleges and universities,
- Church committee chairs,

- Local business owners, and
- Disease-specific groups that focus on minority health risk factors.

An evaluation conducted by The Gerontology Center Research Team at the University of Kansas indicates that the ADDGS³² program has proven effective in its outreach efforts to the caregivers of minority persons with Alzheimer's Disease. About 50 percent of the total families (including care recipients and caregivers) served in the program represent ethnic minorities.

Under the ADDGS, new service programs have been developed for: Hispanic populations in California, Florida, California, and Washington; Native Americans in Montana and Washington; Korean and Chinese communities in Washington; and Asian Pacific Islander groups in Hawaii. **Exhibit VIII.6** presents the Washington Aging and Adult Services Administration Alzheimer's Demonstration Project. Washington has been successful in developing culturally sound services for caregivers through collaborating with experts in delivering minority services.

Tailor Communication Style to the Target Population. Communication approaches must capture the attention of the target audience, employ the dialect and language of the people served, and involve communication styles and vehicles proven meaningful for and accessible by the target audience. Although knowing all of the nuances of a particular culture might be difficult, health care agencies and providers should remain alert to subtle differences. For example, the literature indicates that in contrast to non-minority populations, American Indians might find rushing a social or professional encounter disrespectful because they place no priority on time being rigidly structured. In the American Indian culture, time is more closely related to a sense of being than of doing, and events begin when all expected participants are present. Additionally, in many American Indian cultures, taking time to answer a question posed to an individual is a sign of respect to the questioner and should not be rushed. Asking too many questions could also give the impression of being disrespectful to the speaker.³³

³² See http://www.aoa.gov/alz/profprov/pp_r_eval.asp for evaluation data.

³³ U.S. Department of Health & Human Services, Health Resources and Services Administration (HRSA), LTG Associates, Inc. Crain (2001), Geriatric Training Initiative, Cultural Diversity: American Indians.

Exhibit VIII.6

Partnerships with Ethnic Organizations

Title: Alzheimer's Disease Demonstration Grants to States Program

Affiliation: Washington Aging and Adult Services Administration (AASA)

Status: Operational

Target Population: Chinese, Korean, Hispanic, and Native American caregivers of individuals with Alzheimer's Disease

Approach: This project aims to increase the number of ethnic and culturally diverse persons with Alzheimer's Disease and their families who receive respite and support services. Four local agencies partnered with various ethnic organizations to gain a better understanding of cultural perceptions related to Alzheimer's Disease and to develop culturally sensitive programs. Through these partnerships, the agencies developed culturally appropriate outreach materials and tactics that led to increased service use. The partnerships also provided multilingual Alzheimer's education/training materials, in-home multilingual dementia diagnosis, multilingual outreach programs, caregiver support groups, client advocacy, and interpretation/translation. Ethnic specific project features include an Asian social day care program, adult day services and client advocacy for Spanish-speakers, a Native American outreach coordinator and caregiver support group, and an Alzheimer's/Dementia Support Center for the Chinese community. All of the programs developed through the Demonstration operate today and serve as useful resources as the State continues efforts to support ethnically and culturally diverse caregivers. For more information on these projects, please visit: <http://www.aoa.gov/alz>

Cost/Funding: The program was originally funded through HRSA grants. In 1998, AoA began administering the grants.

Contact Information: Hilari Hauptman, Program Manager, Aging and Adult Services Administration, at haupthp@dshs.wa.gov or (360) 725-2556; Lynne Korte, at kortelm@dshs.wa.gov or (360) 725-2545.

Keeping some general points in mind is useful when developing and using communication vehicles for minority populations:

- Explore the use of community-based media outlets (e.g., minority newspapers and magazines, minority college campus newsletters, local minority radio, cable television programs), and use prepared public service announcements, flyers, and posters as mechanisms for providing service information to minority caregivers.
- Translate program materials to reflect the meaning of the content, rather than literal translation, of existing material, and ensure materials are multi-validated by seeking input from multiple reviewers.
- Develop and widely distribute materials presenting basic service definitions that have comparability in other languages and other cultures.
- Consider and respect language preferences without making assumptions (e.g., many non-native English-speaking individuals are bilingual but prefer to converse in English for certain matters).
- Organize conferences and workshops tailored for a particular minority audience and presented by minority staff.

- Be cognizant of varying levels of technological sophistication and access among minority caregivers, particularly when providing services over the telephone or via the Internet. Some people need more instruction than others, in formats and educational levels meaningful to that sub-population.

All of these communication issues must be considered in relationship to the design and use of burden scale instruments and other caregiver tools. (See **Chapter VI** for more information.)

Sexual Orientation

The following section borrows from David Coon’s article “Caregiving for Families We Choose: Intervention Issues with LGBT Caregivers.” The Lesbian, Gay, Bisexual, and Transgender (LGBT) caregiving experience cuts across age groups and cultural and experiential lines. Prevalence rates reported in studies on the LGBT caregiver population range from 2 percent and 3 percent to upwards of 18 percent to 20 percent.^{34 35} The number is hard to determine because respondents fear social stigma and discrimination associated with LGBT self-identification as well as complexities associated with defining LGBT status.

LGBT adults experience a range of individual-, community-, and organizational-level barriers to accessing appropriate caregiver services. The LGBT population often faces discrimination in the health care system. Research indicates that LGBT people have legitimate concerns about negative views held by medical professionals and the impact these views can have on their health care. Older LGBT caregivers, in particular, have experienced multiple years of discrimination and intolerance. As a result, many LGBT caregivers harbor extremely mixed feelings about openly seeking help and often need to research whether services and organizations will support them, ignore them, or even condemn them.³⁶ **Exhibit VIII.7** presents some of the key barriers this population faces.

³⁴ Tanfer, K. (1993). National Survey of Men: Design and Execution. *Family Planning Perspectives*, Vol. 25.

³⁵ Sell, R.L., Wells, J.A., and Wypij, D. (1995). The Prevalence of Homosexual Behavior and Attraction in the United States, the United Kingdom and France: Results of a National Population-Based Sample. *Archives of Sexual Behavior*. Vol. 24.

³⁶ Kauth, M.R., Hartwig, M.J., and Kalichman, S.C. (2000). Health Behavior Relevant to Psychotherapy with Lesbian, Gay, and Bisexual Clients. In R. Perez, K.A. DeBord, and Bieschke (Eds.), *Handbook of Counseling and Psychotherapy with Lesbian, Gay, and Bisexual Clients*. Washington, DC: American Psychological Association.

Exhibit VIII.7 Barriers to Care for LGBT Caregivers

Individual Barriers	Community Barriers	Institutional Barriers
<ul style="list-style-type: none"> Some LGBT individuals might be reluctant to seek services because of their internalized beliefs about sexuality. Some LGBT individuals might believe their sexuality is a private matter, inappropriate for public discussion, and therefore might resist service providers who either self-identify as LGBT or tailor their services to clients on the basis of sexual orientation and identity. 	<ul style="list-style-type: none"> Formal support systems for older gays and lesbians, let alone for caregivers, are rarely in place, even among larger and more urban LGBT communities. LGBT persons of color might confront racial or ethnic discriminations from within the LGBT community, as well. The reality of limited resources and greater isolation might exacerbate obstacles and issues LGBG caregivers in rural areas and small cities face. 	<ul style="list-style-type: none"> LGBT caregivers and care recipients might be reluctant to reveal their sexual orientations and behaviors to health care professionals for fear of discrimination. Health care systems often defer decision-making to biological relatives rather than to long-time partners, and extended-care settings frequently refuse to allow LGBT partners to visit care recipients.

Source: Coon, D. "Caregiving for Families We Choose: Intervention Issues with LGBT Caregivers." Presented at the American Psychological Association Annual Conference. San Francisco, CA. August, 2001.

Strategies and Program Examples

Provide a Safe Place for LGBT Caregivers. The aging network can incorporate a range of approaches to demonstrate a commitment to serving LGBT caregivers. Network agencies are encouraged to adopt a zero tolerance policy for subtle or overt discrimination and to review employee and client policies to ensure that employment practices are inclusive and that training dollars are allocated for diversity training that encompasses LGBT concerns. A simple "safe place symbol" that is easily identifiable and known to the LGBT community can be chosen to appear in aging network offices, newsletters, and intake forms. This symbol indicates that the organization's staff and service providers have received specific training in working with LGBT issues.

Create LGBT Caregiver Support Groups. Support groups can also be tailored to meet the needs of the LGBT population. ***Exhibit VIII.8*** serves as a good example of a support program that blends the basic elements of grassroots support groups with basic cognitive and behavioral techniques that address specific issues affecting LGBT caregivers.

Exhibit VIII.8

Support Groups for LGBT Caregivers

Title: LGBT Caregiver Support Group

Affiliation: Greater San Francisco Bay Area Chapter of the Alzheimer's Association – San Francisco, California

Status: Operational

Target Population: LGBT caregivers

Approach: Participants in this support group share their feelings about caregiving and its impact on their lives. This project is grounded on the SURE 2 Framework (Sharing and Support, Unhelpful Thinking and Understanding, Reframes and Referrals, and Education and Exploration). Caregivers often discuss the stressors that bring them to the group, whether they be conflict between themselves and significant others, including the care recipients, or conflicts with health care systems. Fellow group members and the facilitator encourage one another to identify what is not working and to share their understanding of how easy it is to get caught up in negative thinking about themselves and their thinking. Caregivers are also encouraged to reframe their thinking and their situations through basic cognitive and behavioral techniques (e.g., basic problem-solving, cost/benefit analyses, avoiding black and white thinking, and positive reframing) and to illicit ideas or perspectives from the group. These ideas include recognition of the obstacles LGBT people face as a result of their sexual orientation or identity, such as difficulty finding LGBT-sensitive in-home health services, day care services, or appropriate placement situations, and the sharing of referrals when competent professionals and organizations are identified. The groups regularly include education about the course of caregiving and upcoming educational seminars sponsored by local groups. Each session reviews explorations of alternative coping strategies, recent referrals tried, and feedback to one another about those referrals. The group closes with at least one strategy or referral for each group member to try to help himself or herself in the caregiving process.

Contract Information: Dr. David Coon, Support Group Leader, at dcoon@ioaging.org, or (415) 750-4180; Toni Morley, ATR, MFT, Alzheimer's Association Support Group Coordinator, at (650) 962-8111.

Train Providers. To communicate a safe environment, the aging network can become skilled in helping LGBT caregivers tell their own stories and describe their relationships with caregiving situations in their own terms. Provider competence requires ongoing training through a variety of vehicles, including workshops and presentations at professional meetings and consultation with groups specializing in LGBT topics.

Sharing one's sexual orientation or "coming out" is an extremely personal choice, and depending on the individual caregiver, might be perceived as a benefit or an additional burden. The coming out process involves balancing a complex set of issues, such as redefinition of self and the management of parents, siblings, and friends. Caregivers, similar to all LGBT individuals, vary in their levels of outness. For example, some individuals are out of the closet with friends but not work colleagues, or vice versa.

Providers can watch for signs of distress and help LGBT caregivers determine if they possess adequate amounts of social support services to effectively manage the process. The provider can accept responsibility for respecting the caregiver's level of outness; however, he or she takes on no responsibility for pulling the person out. As with all

populations, listening to the nuances of language providers' use and their level of experience and training is fundamental for determining their suitability to work with the LGBT population. One strategy for determining provider competence with LGBT clients involves asking employees about their experiences with LGBT people. Additionally, it is extremely helpful if providers are comfortable referring caregivers to local LGBT resources; LGBT clients often consider service providers' knowledge of LGBT community resources a deciding factor when choosing a provider.^{37 38}

Build on Strengths of the LGBT Community. For some caregivers, the LGBT response to the AIDS crisis has created advanced networks of family and friends experienced with caregiving, end-of-life issues, and AIDS-related dementia. However, for other caregivers, the impact of the AIDS epidemic is profound, and the isolation of dementia care is painful. As emphasized throughout this guide, the aging network will need to re-conceptualize social support beyond the family unit—not just by creating and relying on chosen “families,” but by extending support contacts beyond the immediate group to a larger community with services sensitive to the needs of LGBT caregivers.

SPECIAL CAREGIVER CIRCUMSTANCES

Although the term “caregiver” frequently is associated with spouses and adults caring for elderly parents, circumstances involving caregivers other than adults and spouses, as well as care recipients other than the elderly, are common. Sometimes grandparents and other relatives serve as caregivers, and older persons care for adult children or other relatives with developmental disabilities.

Grandparents and Other Relatives Raising Children

Chapter III summarizes the special challenges of grandparents and other relatives caring for grandchildren. Dr. Meredith Minkler's issue brief *Grandparents and Other Relatives Raising Children*, found at www.aoa.gov/carenetwork/IssueBriefs.html, elaborates on the same topic.

The majority of kinship care families comprise grandparents raising their grandchildren; however, many other relatives, including aunts, uncles, older siblings, tribal members, and godparents, are also raising children. By the late 1990s, 5.4 million children were living in grandparent- or other relative-headed households. In almost 40 percent of these cases, the children's parents were absent.³⁹ The tremendous increase in kinship care families is attributable to many factors, including substance abuse, the rise in single-headed households, death, incarceration of the child's parent, child abuse, neglect, teen

³⁷ Liddle, B. (1997). Gay and Lesbian Clients? Selection of Therapists and Utilization of Therapy. *Psychotherapy*, Vol. 34.

³⁸ Matteson, D. (1996). Counseling and Psychotherapy with Bisexual and Exploring Clients. In B. Firestein (Ed.), *Bisexuality: The Psychology and Politics of an Invisible Minority* (pp. 185–213). Newbury Park, CA: Sage Publications.

³⁹ Casper, L.M. and Bryson, K. (1998). *Co-resident Grandparents and Their Grandchildren: Grandparent Maintained Families*. Washington, DC: Bureau of the Census.

pregnancy, divorce and health issues.⁴⁰ The typical relative caregiver is a married woman living on modest means but above the poverty line. Single women, African Americans, and the poor, however, have a greatly increased likelihood of taking on this role.⁴¹

Strategies and Program Examples

A number of implications for practice can be drawn from the experiences of the aging network and health and social service providers, through a rapidly burgeoning research base, and through the voices of grandparent caregivers and their families. The following principles and approaches can establish the framework for meeting the needs of grandparent caregivers and their families.

Establish Implementation Goals Based on Needs Identified by Grandparents and Other Relative Caregivers. Grandparent caregivers make articulate spokespersons for their own needs and concerns and those of their families and fellow caregivers. New programs that begin with the agenda of grandparent caregivers are far more likely to achieve success. Relative caregiver town halls and forums, focus groups, and surveys and other data collection methods help determine the needs of grandparent caregivers in a given geographic area.

Develop, Publish, and Disseminate Information. Many states take advantage of grants awarded by the Brookdale Foundation, which sponsors the Relative as Parents Program (RAPP) to facilitate information dissemination through a variety of vehicles, including comprehensive resource guides for relatives raising children. The guides typically use a question-and-answer format and cover topics such as childcare, education, custody, other legal issues, and contact information for a range of programs and resources. Washington State partnered with the state's AARP and Casey Family programs to develop its RAPP initiative. A key element of the initiative involved the development of *Relatives as Parents: A Resource Guide for Relatives Raising Children in Washington State*. **Exhibit VIII.9** offers a summary of Washington's RAPP initiative.

Seek and Develop Creative Partnerships. A major factor in the success of the Brookdale Foundation's RAPP is the requirement that funded entities work collaboratively with other agencies and organizations, including those outside the aging network. By partnering with voluntary children's and youth organizations, faith-based entities, public sector programs such as Head Start and Section 8 Housing, and local hospitals and schools, SUAs, AAAs, and ITOs can vastly increase the resource base, visibility, and effectiveness of their NFCSP efforts. Partnering with agencies or programs without limits for client age might enable the programs developed to better meet the needs of the many relative caregivers below age 60.

⁴⁰ Minkler, M., Deurr-Berrick, J., and Needell, B. (1999). *The Impact of Welfare Reform on California Grandparents Raising Grandchildren*. Berkeley, CA: Center for Social Services Research, School of Social Welfare, U.C. Berkeley.

⁴¹ Minkler, M. (2001). *Grandparents and Other Relatives Raising Children: Characteristics, Needs, Best Practices and Implications for the Aging Network*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Exhibit VIII.9

Information Dissemination

Title: Washington Relatives as Parents Program (RAPP) State Initiative

Affiliation: Washington Aging and Adult Services Administration (AASA)

Status: Operational

Target Population: Grandparents and other older adults raising children

Approach: The RAPP state initiative serves grandparents and relatives raising children by providing informational resources and services through a range of mechanisms, including a free resource guide. *Relatives as Parents: A Resource Guide for Relatives Raising Children in Washington State* describes available services and provides general information on raising children. To date, more than 23,000 copies of this 44-page guide have been distributed to caregivers and professionals. AASA sponsors regional workshops co-facilitated by experts, such as attorneys and paralegals, social service providers, and legislative staff. AASA also co-sponsored a national Grandparents Raising Grandchildren satellite teleconferences (linked to 19 sites) for caregivers and professionals who serve them. The state maintains a RAPP resource library containing videos, books, and other material for caregivers and professionals working with this population. In collaboration with the state's University Cooperative Extension Program, the state has also established a Web site that contains a statewide database of support groups, legal services, and links to other relevant resources and special events that might interest relative caregivers and their families. Other initiatives include creating an interagency, public/private, statewide RAPP coalition (comprised of more than 40 agencies) to provide means for networking and support; development, advocacy, and maintenance of kinship caregiver support groups; and legal advocacy and education for kinship caregivers.

Cost/Funding: AASA, as well as several local partnering organizations, received grants from the Brookdale Foundation's RAPP.

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Maintain Open Communication with Advocacy Organizations. Achieving substantive improvements in the well-being of relative caregivers and their families frequently requires new legislative and policy changes, framed in an intergenerational context that support, rather than penalize, these families. Although SUAs, AAAs, and ITOs generally cannot directly advocate legislative changes, they are in an excellent position to help document the need for new policy directions. Members of the aging network can help create the knowledge base vital to organizations like AARP, Generations United (GU), the Child Welfare League of America (CWLA), and the Children's Defense Fund (CDF), as they work to promote needed policy change.

Assist Caregivers in Gaining Access to Needed Programs. Several SUAs have developed creative methods to assist grandparent caregivers in gaining access to programs and services for themselves and the children in their care. Ohio's Department of Aging funded a kinship care "navigator" program to help caregivers in both negotiating the legal system and accessing benefits. Ohio's creation of a toll-free hotline for kinship caregivers and Kentucky's Senior Health Insurance Information Program (SHIP) 1-800 hotline represent other creative approaches that SUAs might emulate.

Provide Respite Services. Although respite from the demands of caregiving has proven among the most desired services for grandparent caregivers, few existing programs address the respite needs of relative caregivers. A notable exception on the state level involves the Oklahoma Respite Resource Network (ORRN), created in part through the Aging Services Division of Oklahoma’s Department of Human Services. For more than a decade, the ORRN has provided respite to grandparents and other caregivers with low to moderate incomes. Caregivers enjoy wide discretion in the choice of respite care providers.

Facilitate Support Groups. Aided by a seed grant from the Brookdale Foundation Group and contracting with a statewide nonprofit family service agency, Children and Families First, the intergenerational program of Delaware’s SUA began the Family Circles education and support group program for relative caregivers in 1997. Operating six support groups throughout the state, the program provides a significant model partly because of its success in insuring the sustainability of these groups. Children and Families First has been able to maintain support groups after the termination of state funding.

Caregivers of Children and Young Adults with Developmental Disabilities

The following section borrows from Dr. Matthew P. Janicki’s issue brief *Coordinating Systems Servicing Caregivers of Children and Adults with Developmental Disabilities*, found at <http://www.aoa.gov/carenetwork/IssueBriefs.html>. Approximately 1.9 million children and adults with developmental disabilities live with their parents. Approximately 25 percent of these caregivers are age 60 and older. Many older caregivers are mothers who have provided care throughout the life of their adult son or daughter.⁴² While the NFCSP is effectively restricted to older caregivers of children with MR/DD, it is useful, particularly from a coordination standpoint, to look at this broader range of caregivers.

In the past, state developmental disabilities’ agencies designed family support services primarily with the needs of younger parents of children with developmental disabilities in mind, while support services for older caregivers were extremely limited. This situation is now changing, however, because current belief holds that most individuals with an intellectual disability enjoy life expectancy typical of other people and continue to rely on some level of support from their parents. Additionally, there continues to be an increasing number of older caregivers each year with younger generations of older people remaining healthier and less impaired longer than previous generations. Each of these factors makes it critical to provide support for elder individuals caring for both children and adults with developmental disabilities.

Many challenges confront older parents as they provide care to *young children* with developmental disabilities, including a range of system issues such as shortages of special

⁴² Janicki, M. (2001). *Coordinating Systems Servicing Caregivers of Children and Adults with Developmental Disabilities*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

education teachers, inappropriate level of services, and inadequacies in special education programs. Other challenges include deficiencies in responsiveness to Individual Education Programs (IEP)⁴³ and abuse and neglect in the school system. Elderly parents are typically the very parents who have failed to benefit from recent policies promoting mainstreaming, equal education, supported employment, and independent living options for children and adults with developmental disabilities. Therefore, these caregivers might feel less comfortable receiving assistance or less familiar with the system to know where to turn for support.

As children with developmental disabilities become *young adults*, older parents worry about what will happen to their family member if they become incapable of caring for him or her, and they identify this concern as an ever-present source of stress and anxiety. Some want to have a plan for the future but often feel too overwhelmed by their day-to-day responsibilities as caregivers to focus on the problem. In addition to facing problems associated with the caring they have provided all of their lives, older caregivers are faced with issues related to their own aging and changing life situation, such as changes in physical health and financial resources.

Clearly, a need exists to locate, inform, and draw older caregivers of children and adults with developmental disabilities into the aging network and to establish mechanisms that link them to family support networks often available through aging, social services, or disability agencies. The majority of caregivers providing in-home support for people with a developmental disability experience the same needs as other families in caring situations, the main difference being that they are lifelong caregivers. As they age, they want:

- Services that meet their immediate needs (e.g., respite, housekeeping assistance, transportation, and emotional supports),
- Assistance with obtaining financial planning information (e.g., information on entitlements, guardianship, and trusts) and financial supports or determinations of eligibility,
- Help with negotiating the health and social service systems and advocacy for obtaining services for which they qualify, and
- Help with making decisions about their life or the life of the person for whom they are caring.

Strategies and Program Examples

Challenges for the aging network responding to the mandates of the NFCSP include developing mechanisms for effective outreach to the older parents of the developmentally

⁴³ The Individuals with Disabilities Act (IDEA, Public Law 105-17) is the federal law mandating that all children with disabilities have available to them a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. Part B of IDEA requires that schools provide an individualized education program (IEP) to all children with disabilities.

disabled, enhancing their information and assistance (I&A) processes, providing support coordination and general assistance, and, when appropriate, linking these families to the local developmental disabilities providers.

Determine Existing Needs. In undertaking an initiative to serve older caregivers of individuals with a developmental disability under the NFCSP, first determining the number and nature of such families in the catchment area is helpful. In addition, the following questions should be investigated:

- What are the local needs of this population, and which are most immediate?
- What resources currently exist in the community to help these families?
- What are the disability and social services networks doing to help these families and caregivers?
- How can the aging network interface with existing efforts or spearhead the initiation of a new effort?

Another key consideration is whether to undertake this type of initiative within the aging agency or to contract it out. Whether the aging agency does direct work, normally contracts out, or works through other agencies might govern this decision.

Continue to Partner with Developmental Disability State Agencies. The aging network can build on their substantial experience in creating effective partnerships with developmental disability agencies to help implement local or regional disability-related activities under the NFCSP. Developing such partnerships can involve a number of approaches, including:

- Inviting representatives of aging and developmental disability agencies to serve on a planning committee or task group or to speak to a provider/consumer group or at an interagency conference;
- Formalizing a relationship between the aging service agencies, developmental disabilities agencies, and the state's developmental disabilities planning council through mutually agreed roles and responsibilities and sharing of directives that stem from an interagency memorandum of understanding (MOU) or agreement;
- Fostering interagency cooperation with budgetary submissions and allocations and regulatory reviews; and
- Establishing an interagency task group that examines a particular long-term care problem (e.g., housing, adult day care, family assistance) that involves both dependent elderly and older disabled populations.

Working within the greater disability system to build the NFCSP initiative can allow the aging network to rely on providers as resources they can call on when the caregivers or care recipient needs assistance. The disability system can also share financial resources and stretch the available funds under the NFCSP, preventing duplication of effort or waste of scarce resources. ***Exhibit VIII.10*** summarizes a Texas Department of Aging initiative that represents a good example of an effective collaboration with the network and community developmental disability agencies.

Exhibit VIII.10

Outreach and Linkages with Developmental Disability Agencies

Title: Support for Aging Individuals with Developmental Disabilities

Affiliation: Texas Department for Aging (SUA), Texas Council for Developmental Disabilities

Status: This demonstration project ended in 2001; however, the participating AAAs are continuing to build on this effort under a new statewide program (Regional Access Plan).

Target Population: Aging individuals with developmental disabilities and caregivers of individuals with developmental disabilities

Approach: This five-year project has allowed nine Texas AAAs to develop collaborative work groups with local developmental disability service providers and family caregivers to explore ways to increase their collective capacity and to meet the needs of people growing older with developmental disabilities. The findings from this project were compiled into a report entitled “Aging with Developmental Disabilities: The Texas Project.” The report includes individual AAA case studies, as well as findings related to best practices for building capacity and collaboration across providers, and lessons learned and outcomes achieved. This report is available through the Texas Department of Aging.

Cost/Funding: The state’s Developmental Disabilities Council funded this project.

Contact Information: Linda Fulmer, Texas Department of Aging Contractor, at abana@falsh.net or (817) 451-8740; Gary Jessee, Director of AAA Support and Operations, at gary.jessee@tdoa.state.tx.us or (512) 424-6857.

ENVIRONMENTAL CONDITIONS

A number of environmental conditions play a role in defining the needs of particular caregiver groups, including individuals faced with balancing the dual roles of working part-time or fulltime and serving as caregivers. Caregivers living in rural areas also experience unique barriers to receiving appropriate services. And, long-distance caregivers experience obstacles specifically associated with being geographically removed from the care recipient.

Working Caregivers

Based on workplace surveys, individuals with current elder care responsibilities have been estimated at 13 percent of the workforce, and those involved in caregiving at some point during the past 12 months at 25 percent. Regardless of the actual prevalence rate among U.S. workers, we can expect to see higher numbers, perhaps double the numbers, involved in providing care in the future due to the aging of our population and the increased number of women in the workforce.⁴⁴

Although little systematic research has been conducted explicitly on the needs of working caregivers, existing research and anecdotal reports from working caregivers indicate the perceptions, priorities, and preferences of working caregivers. Flexibility in the work

⁴⁴ Neal, M.B. and Wagner, D. (2001). *Working Caregivers: Issues, Challenges and Opportunities for the Aging Network*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

place, particularly in the scheduling of work hours, constitutes one need. A second set of needs centers on I&A—an area in which the aging network exhibits considerable expertise. A third area of need involves emotional support and a fourth, other tangible assistance, such as assisting caregivers with health insurance paperwork.

Strategies and Program Examples

Working caregivers require a way to access information, referrals, advice, case management assistance, emotional support, and tangible assistance that minimizes interruptions to their work, supports involvement in caregiving, and maximizes time efficiency. Following are strategies the aging network can use to respond to the needs of this population.

Facilitate Access to Information, Assistance, and Referral. Most working caregivers need information on the community services available to support the needs of elders because they possess little or no previous experience with negotiating the aging services system. Working caregivers also need help with legal, financial, and health insurance matters and the paperwork associated with these responsibilities (e.g., securing and completing the legal forms for durable power of attorney, wills, and reverse mortgages). The aging network can play an important role in providing useful information to working caregivers about caregiving, health conditions, and where to turn for help. The aging network can also provide assessment and case management services to evaluate the elder's needs, determine eligibility and payment options, and package the required services.

To provide resources for caregivers, the aging network can partner with employers. Offering I&A—notifying working caregivers about specific services available to them and their elders and helping them locate these services—represents the most common form of direct services employers provide. Generally, the service is performed by an in-house employee assistance program, or by a private for-profit organization. The aging network can link to caregivers directly by publicizing their existing information lines. Also, the aging network can tailor specific services for some employers on a contractual basis. Using the network as a vendor might prove especially attractive to small employers for whom in-house programs are unfeasible and contracted services are too expensive.

Educate Caregivers. A variety of educational programs and written materials assist employees with caregiving demands. The aging network and contract agencies can reach working caregivers either directly or through their employers. An effective way to inform a large number of employees about caregiving issues and resources is through newsletters and inserts in paycheck envelopes. Single articles can be prepared or entire newsletters can focus on caregiving concerns. Some businesses have implemented caregiving fairs, along the lines of health fairs, where employees can obtain information from a variety of different agencies and organizations at one time. Employees can stop at booths, talk to service providers, and obtain written information about specific community resources. The network can organize such fairs for the employees of one large employer or several smaller employers.

Inform Employers about Working Caregivers' Need for Flexibility as well as Benefits of Supporting Caregivers. Most network agencies operate only during the regular business hours. As a result, many working caregivers have to either use work time for making telephone calls or take time off to gain access to services for their elders or themselves. Working caregivers routinely note the importance of both flexible work hours and being able to take unscheduled time off when needed to handle caregiving responsibilities. A recent study found that lower levels of family-related supervisor support were associated with higher levels of work-family conflict. Similarly, a less supportive workplace culture was associated with work-family conflict.⁴⁵ Network agencies can play an important role in facilitating workplace flexibility by educating employers and providing evidence of benefits to employers.

Enhance Internet Services. A tremendous amount of information on work-family issues is available on the Internet. Providing employees with access to a computer and printer to obtain the information they need is an economical method for employers to support their employees with elder care responsibilities. Multnomah County, Oregon's local AAA developed the idea of facilitating access to Web resources by creating and distributing a desktop icon for installation on employees' computer screens that would link them to the agency's Web site and also provide links to other useful Web sites. A compact disk (CD) containing Web site information is made available to employees without access to the Internet.

Negotiate with Employers to Provide Direct Services for Elderly Care Recipients. Some companies help employees deal with their dependent care needs directly by providing subsidies, vouchers, or discounts for particular services, such as adult day services and respite programs or by sponsoring onsite or near-site day care facilities. AAA contract agencies can make arrangements with employers for working caregivers to use their adult day services or respite services at a discount or through subsidies or vouchers. Network agencies can also assist in establishing registries of respite care workers. For the purpose of facilitating other needed services, the network can help employers set up cooperatives among employers. AAAs, however, must consider the state's policies on such arrangements. ***Exhibit VIII.11*** presents examples of efforts under way in Texas and Washington, DC, to improve access to information and quality services and providers for working caregivers.

⁴⁵ Barrah, J.L. and Shultz, K.S. (2001). Elder Care Based Work-Family Conflict: Antecedents and Consequences. Paper presented at annual meeting of the Gerontological Society of America, Chicago, IL.

Exhibit VIII.11 Public/Private Partnerships

Title: Elder Service Network

Affiliation: Dallas, North Central, and Tarrant County AAAs; AT&T Communications; Workers of America; and International Brotherhood of Electrical Workers

Status: Developmental

Target Population: Working caregivers

Approach: AAAs partnered to respond to a request for proposal (RFP) issued by AT&T to develop the Elder Service Network, an initiative to provide more convenient access to services for working caregivers. The program will involve a study of working caregivers' needs in the participating AAA service areas. The study will also examine the costs and quality of available services and credential providers to develop a preferred provider network. Care management serves as a significant component of the Elder Service Network program because care managers will provide a one-stop shop in assessment, service arrangement, and unified billing for network services.

Cost/Funding: The estimated project cost is \$80,000 per year. Funding is provided as follows: 1) a \$40,000 grant from AT&T Family Care Development Fund, a joint project of AT&T, the Communications Workers of America, and the International Brotherhood of Electrical Workers; 2) \$40,000 per year from NFCSP funds; and 3) client revenues. Grant funds will be used to employ a part-time program coordinator. NFCSP funds will be used for the research, market survey, quality indicator development and implementation, and development of an expanded resource database, including for-profit providers. After two years, planners intend the program to sustain itself through private pay revenue.

Contact Information: Donnie Van Ryswyk, Dallas AAA, at doni@winfo.com or (817) 695-9193.

Title: FannieMae Eldercare Initiative

Status: Operational

Affiliation: IONA Senior Services, Washington, DC; FannieMae Corporation

Target Population: Working caregivers

Approach: IONA Senior Services is under contract with FannieMae to provide a clinical gerontological social worker, "Eldercare Consultant," to FannieMae employees seeking assistance with financial, medical, and legal issues surrounding caregiving. The Eldercare Consultant also provides educational seminars related to aging and caregiving. IONA assisted Fannie Mae in developing an Eldercare Kit, including caregiving related resources and brochures, to distribute to employees. The program has served about 10 percent of the company's 4,000 employees.

Contact Information: Daniel Wilson, Director of Social Services, IONA Senior Services, at dwilson@iona.org or (202) 895-9436. For more information, please visit <http://www.iona.org>.

Make Support Coordination Service Available. Support coordination for working caregivers who need help in assessing, addressing, and monitoring an elder's multiple needs is more intensive and individualized. Some employers offer it via their internal employee assistance program or, more typically, through an external vendor. Network agencies can provide this service to employers for their employees, ideally at the workplace, the agency, or both, with expanded evening and weekend hours.

Facilitate Workplace Support Groups. Aging network staff can assist in organizing or conducting support groups or both. Such groups typically provide information, as well as emotional support, to members and may be facilitated by professionals or peers. Based on evaluations of demonstration projects, caregivers prefer that some support groups be held after work, as opposed to on the lunch hour; that separate groups for management and non-management be held to enhance willingness to discuss problems; and that groups be promoted as “informational” to overcome discomfort with the stigma overtones of a “support group.”

Rural Caregivers

The overall rural population has increased significantly over the last fifty years and has been aging rapidly as a result of: the desire to “age-in-place,” out-migration of youth from agricultural and mining areas, and the immigration of elders from urban areas. Caregivers provide more than 70 percent of both direct and indirect care services for poor, socially isolated, underserved, frail and chronically ill elders in rural communities and the need to support these informal caregivers is a crucial rural health care program planning issue.⁴⁶

Both attitudinal and structural barriers exist for caregivers living in rural communities. Community norms and cultural attitudes serve as key factors influencing service acceptability in rural communities. Research studies highlight several attitudinal barriers for rural caregivers. Barriers include: 1) stigma and guilt about seeking help and receiving services, 2) value of self-reliance, 3) belief that family members should assume responsibility for care, 4) reluctance to seek services until a crisis occurs; 5) denial of symptoms, and 6) ageism. These values and beliefs, and the stigma particularly associated with the use of mental health or counseling services, often contribute to the low use of formal services in rural populations.⁴⁷

Several structural barriers also affect help-seeking behavior and the experience of being a caregiver. Most rural communities possess limited fiscal resources and infrastructure (e.g., program planners, trained workers, transportation) necessary to develop their own community-based programs. Key barriers include:

- Lack of coordination in the service delivery system;
- Cost of services;
- Service agencies that are overburdened, understaffed, or unavailable;
- Distance and lack of access to transportation;
- Restrictive reimbursement policies for services;
- Lack of access to comprehensive diagnostic and assessment services; and

⁴⁶ Buckwalter, K. and Lindsey Davis, L. (2001). *Elder Caregiving in Rural Areas*. Issue Brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

⁴⁷ Connell, C.M., Kole, S.L., Avey, H., Benedict, C.J., and Gillman, S. (May/June 1996). Attitudes about Alzheimer’s Disease and the Dementia Service Delivery Network Among Family Caregivers and Service Providers in Rural Michigan. *American Journal of Alzheimer’s Disease*.

- Family physicians who sometimes make no referrals for services.⁴⁸

Rural caregivers also frequently report frustrations related to use of needed services, such as being put on a waiting list for services that are needed immediately and difficulty understanding complex reimbursement policies.

Strategies and Program Examples

Collaborate with Rural Caregivers, Community Leader, and Staff Reflecting the Values of the Community. Demonstration projects in rural communities across a variety of states indicate that successful rural caregiver assistance programs are developed in collaboration with rural caregivers, endorsed by community leaders, and staffed by persons familiar with the cultural and social values of the community. Many communities also partner with, or refer caregivers to, entities in the community that have traditionally provided important support systems to rural families. For example, many network agencies take advantage of educational programs provided by county cooperative extension centers under the land grant system. Cooperative extension centers have a long history of providing educational services to families. The North Carolina Cooperative Extension Service provides a how-to educational approach for caregivers (e.g., seminars related to managing stress associated with caregiving and addressing caregiving issues at the end of life). ***Exhibit VIII.12*** presents program characteristics and persons to involve for planning successful rural caregiver assistance programs.

Exhibit VIII.12
RURAL Caregiver Program Planning Model

	Desired Program Characteristic	Program planners must ensure rural caregiver assistance programs.
R	<u>R</u>elelevance	Involve caregivers in identifying program service needs and program relevance.
U	<u>U</u>nity	Integrate new program offerings with existing community services to ensure the new program does not compete with or duplicate existing programs.
R	<u>R</u>esponsiveness	Respond to the ethnic and cultural identity and traditions of elders, caregivers, and residents in the community.
A	<u>A</u>ccess	Enhance program access for caregivers through timing, location, transportation, and publicizing new services.
L	<u>L</u>ocal leadership	Include local leadership (e.g., nurses, social workers, physicians, ministers, church groups, civic leaders, other community service workers) in supporting and publicizing the program.

Source: Buckwalter, K. and Lindsey Davis, L. (2001). *Elder Caregiving in Rural Areas*. Issue Brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

⁴⁸ Connell, C.M., Kole, S.L., Avey, H., Benedict, C.J., and Gillman, S. (May/June 1996). Attitudes about Alzheimer's Disease and the Dementia Service Delivery Network Among Family Caregivers and Service Providers in Rural Michigan. *American Journal of Alzheimer's Disease*.

Train Caregivers. Similar to other caregivers, caregivers of elders in rural communities need assistance with acquiring a core set of skills that will enable them to accurately monitor and interpret symptoms, successfully manage medical regimens, provide hands-on care, find and use appropriate resources, and make sound caregiving decisions, all while providing affective support and encouragement to the chronically ill or disabled. Thus, rural caregiver assistance programs traditionally combine information on aging and chronic illness with skills training on providing home care as well as affective support, counseling, and periodic respite for the caregiver.

Employ Innovative Information Technologies. Information technologies might answer access challenges for both rural communities and long-distance caregivers. Promising are communication and information technologies to expand the reach of case managers and improve the coordination, access to, and quality of care in rural communities. Because of increasing pressures on service infrastructures, case managers face constant challenges in finding, getting, and monitoring services for clients and educating caregivers to improve their care decisions. Several potential benefits of telehealth technologies exist for support coordinators:

- Reductions in travel time to adequately assess and monitor clients
- Increases in numbers of clients who can be effectively monitored
- Opportunities to more frequently conduct educational sessions and provide technical and emotional support to homebound clients and their caregivers
- Ability to readily access through the Internet client records, educational and informational materials, communications with colleagues, and other activities that decrease isolation

Benefits for caregivers include the following:

- Closer contact with case managers
- Opportunities for interaction with others in similar circumstances
- Timely access to face-to-face contact when needed for assistance or support
- Reductions in time and energy needed to travel for health monitoring
- Assistance with the supervision and monitoring of in-home workers

Form Partnerships. Forming creative partnerships might involve encouraging local high schools and nearby community colleges to offer credit courses in visiting and working with frail elders and their caregivers, encouraging urban health profession schools to include rural family caregiving courses in the curricula, and creating articulated models of caregiver assistance programs between urban and rural health care centers. The Seamless Delivery System Project, illustrated in ***Exhibit VIII.13***, serves as a good example of a collaborative program model designed specifically to meet the needs of rural caregivers.

Exhibit VIII.13

Building a Seamless Dementia-Specific Service Delivery System in Rural Iowa

Title: Seamless Dementia-Specific Service Delivery System Project (ADDGS Project)

Affiliation: Collaboration among the Iowa Department of Elder Affairs, the University of Iowa's College of Nursing and Center on Aging, the AAAs, Alzheimer's Association chapters, and Resource Link of Iowa

Status: Operational

Target Population: Rural Caregivers

Approach: This AoA funded project provides expanded in-home services to rural Iowans and their caregivers who are affected by Alzheimer's Disease and related disorders (ADRD). The project uses a community organization model, developed by the Big Sioux chapter of the Alzheimer's Association, to help rural communities create care systems that meet their unique needs in eight rural counties. Two assumptions underlie the approach: 1) if services are to be accepted within rural communities, the services must be designed by the community; 2) if the community values the services, it will refer neighbors to them. This program designates nurse care managers (NCMs) trained to provide in-home services, education, and support, to caregivers of ADRD. The NCMs work with the local case management system to coordinate available services, refer clients to funding sources, assist with community development programs, and report to the AAAs.

Cost/Funding: This program is funded through a three-year AoA ADDGS grant from 2000–2003.

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Provide Services that Compensate for Geographic Isolation of Rural Areas. Programs that compensate for geographic isolation through the combination of periodic home visits and innovative information technologies and telecommunications (e.g., peer caregiver telephone networks, telemedicine and telenursing contact systems) are critical to helping rural caregivers. Individuals also need to have access to preventive counseling and supportive mental health services for distressed and depressed caregivers, transportation to access community-based programs offerings, and caregiver “health promotion” programs in community centers (e.g., blood pressure checks, mammograms) during weekday and daytime hours. Caregivers can combine their self-care activities with a doctor appointment for the elder during a trip into town.

Long-Distance Caregivers

The complexities of providing support to care recipients are compounded for long-distance caregivers, who often must make decisions and implement actions without face-to-face assistance. Most long-distance caregivers are unable to visit frequently and cannot provide care in the home. Adult children, as well as other long distance relatives, often

experience guilt associated with spending less time with their parents and feelings of being overwhelmed by the challenges of arranging services long distance.⁴⁹

Long-distance caregivers have numerous concerns, including lack of knowledge about where to begin obtaining information about accessing services to meet their needs and care-recipient needs. Rather than contacting an AAA, many of these caregivers turn to neighbors, friends, and doctors for information. These individuals are less likely to be as informed as the AAA, and thus, the long-distance caregiver continues to experience difficulty in accessing services. Common needs of long-distance caregivers include the following:

- Assistance with determining what services are needed for the care recipient and how to coordinate the range of needed services
- Knowing when to visit the care recipient and how to monitor care recipient activities
- Learning how to identify and rely on other formal and informal caregivers for assistance
- Receiving ongoing information on the care recipient's physical, emotional, and mental health status from clinicians and supporting agencies
- Making the most of visits to the care recipient's home (e.g., making appointments with physicians, lawyers, and financial advisers to facilitate decision-making; meeting with the care recipient's local support system to hear observations about how the care recipient is doing; understanding whether behavioral changes, health problems, or safety issues have occurred; taking time to reconnect with the care recipient)
- Moving a care recipient into a nursing home and monitoring care for a loved one in a home
- Resolving family conflicts

Strategies and Program Examples

Link Long-Distance Caregivers to Community Resources (e.g., toll-free telephone numbers and Web sites). Long-distance caregivers must be made aware of Eldercare Locator, a national directory assistance designed for seniors and caregivers providing local support services. Eldercare Locator is piloting a program that involves transferring callers from Eldercare Locator directly to the AAA, thereby eliminating the cost of a long-distance telephone call. In addition to Eldercare Locator, long-distance caregivers should be made aware of other resources, including the following:

- National Alzheimer's Association
- American Association of Home and Services for the Aging
- National Adult Day Services Association

⁴⁹ AARP, Long-Distance Caregiving <http://www.aarp.org/confacts/caregive/londistance.html>.

- National Association for Home Care
- National Council on Aging Benefits
- National Association of Professional Geriatric Care

All of these resources can help long-distance caregivers identify services in local communities.

Provide Mechanisms for Long-Distance Caregivers to Receive Regular Updates on Care Recipient's Health Status from Clinicians and Other Providers. The Los Angeles Alzheimer's Association operates a program, highlighted in ***Exhibit VIII.14***, that makes it possible for long-distance caregivers supporting individuals with Alzheimer's Disease living in Los Angeles to regularly receive information on the health of their relative. The aging network can play an important role in easing the burden of long-distance caregiving by establishing case management systems that ensure ongoing and frequent flow of information from the aging network to the caregiver.

Exhibit VIII.14

Information Exchange with Long-Distance Caregivers

Title: Long-Distance Caregivers Project

Affiliation: Alzheimer's Association of Los Angeles, California

Status: Operational

Target Population: Long distance caregivers of individuals with Alzheimer's Disease

Approach: This program provides staff with the resources to contact and share information with long-distance caregivers (individuals living outside the Los Angeles area) of individuals with Alzheimer's Disease living in Los Angeles area. The project provides caregivers with a professional consultant to assist in caregiving tasks and access to legal services, a Web site, support groups, safe return registration, and a resource guide and workbook. Caregivers report increased comfort levels regarding the well-being of their loved ones because the information is coming directly from professionals, rather than solely through the care recipient.

Cost/Funding: The Archstone Foundation of Long Beach, California, funds this project.

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